

Workforce Tools is a series of publications for people concerned with improving the quality and stability of the home- and community-based direct-care workforce. The Paraprofessional Healthcare Institute (PHI) produced this issue, under sub-contract to the MED-STAT Group, Inc. (CMS Contract No. 500-96-



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006, Task Order No. 2), for the Centers for Medicare & Medicaid Services project *Research on the Availability of Personal Assistance Services*.

As more people living with disabilities choose to live in home- and community-based settings, the high rates of vacancies and turnover of direct-care workers are becoming an increasingly critical public policy issue. In response, CMS is funding research to help states develop a workforce that can support people living with disabilities and long-term illnesses. As part of the research effort, PHI is collecting resources to help state agencies, service providers, and individual consumers recruit, train, and retain home care and personal assistance workers. These resources are available in an on-line database housed at

www.directcareclearinghouse.org/pas/index.jsp

Direct Care Worker Associations: Empowering Workers to Improve the Quality of Home- and Community-Based Care focuses on the valuable role professional associations for direct-care workers can play in stabilizing the workforce, and is a valuable tool to help people who want to establish or support associations in their states. It is available on-line at

www.directcareclearinghouse.org/download/dcwassocs.pdf

Direct Care Worker Associations:

Empowering Workers to Improve the Quality of Home- and Community-Based Care

The demand for direct-care workers to provide home- and community-based services is growing fast. Not only are privately paying consumers increasingly seeking out such services, but the U.S. Supreme Court's *Olmstead* decision and President Bush's *New Freedom Initiative* have mobilized states to provide more long-term care in homes or other community-based settings. The U.S. Department of Labor expects personal and home health aide jobs to grow from 414,000 in 2000 to 672,000 in 2010.¹

In most parts of the country, however, supply is already lagging behind demand. Low wages, the paucity of affordable health insurance and other benefits, inadequate training, a shortage of supportive supervision, and limited opportunities for career advancement discourage new candidates from entering the field and cause many experienced workers to leave. Also contributing to low morale and high turnover are a tendency for both employers and the public to see the work as unskilled and menial and to treat workers disrespectfully.²

In recent years, policymakers and employers have tried a number of initiatives to improve the quality of the job in order to ensure an adequate supply of qualified caregivers. These include Medicaid-funded "wage pass-throughs" to raise pay for direct-care workers,³ specialized training, and career ladder programs⁴ that give direct-care workers a way to advance without leaving the profession.

In addition to these changes in workforce practice and policy, some have sought to involve workers more directly in advocating for themselves and their work through the formation of professional associations. Direct-care worker associations can give individual workers a means of gaining additional skills, accessing support and recognition, and networking with peers. In addition, they can raise awareness of the value of caregiving work and help workers develop the leadership skills they need to become actively involved in discussions about long-term care policy and workplace practices.

This issue brief provides an overview of professional associations for direct-care workers,⁵ including:

- Their history and achievements,
- The benefits for members and for other stakeholders,
- Organizational models that have proved successful, and
- Tips on how to organize and sustain such associations.

History and Achievements

The first professional association for direct-care workers, Norton, Ohio-based Career Nurse Assistants Programs, Inc. (CNAP),⁶ was founded in 1977. CNAP, whose worker members are known as the National Network of Career Nursing

Assistants (NNCNA), has about 6,000 individuals and groups on its mailing list. Thousands of employers participate in its annual Career Nursing Assistants' Day and Career Nursing Assistants' Week, which seek to upgrade nursing assistants' status in the workplace. The group also runs an annual leadership training program for members.

Like the Iowa CareGivers Association (ICA),⁷ which followed in 1992, and NAGNA,⁸ which was founded in 1995, NNCNA was created to serve nursing assistants who worked in nursing homes. Since then, however, NNCNA and the ICA have branched out to include direct-care workers in other long-term care settings, and NAGNA recently created associate memberships for other nursing home staff.

The ICA, which is based in Des Moines, has approximately 1,500 direct-care worker members. It sponsors widely cited research on issues affecting direct-care workers, runs peer mentor training in association with area community colleges, and hosts an annual conference for workers. It also serves as the lead organization for Iowa's Better Jobs Better Care (BJBC) demonstration project.⁹

Joplin, Missouri-based NAGNA represents more than 30,000 CNAs. Many are enrolled under the group's Facility Membership program, in which nursing homes pay an annual fee (the average is about \$4,000) in order for their CNAs to receive NAGNA benefits, including individual subscriptions to the association's bimonthly newsletter and access to periodic workshops conducted by NAGNA consultants. At most participating nursing homes CNAs form NAGNA Leadership Teams, which meet regularly to develop facility-based CNA recognition programs or other projects. Other NAGNA members pay for their own individual memberships, which entitle them to a broader range of benefits, including a national discount pharmacy network, free behavioral counseling, and a toll-free Resource Call Center that helps members access financial assistance through government programs and other needed supports. NAGNA also offers continuing education through on-line and correspondence courses.

A number of other direct-care worker associations, many of them for home- and community-based workers, have followed these leaders.¹⁰ While most were started by long-term care nurses, state agency staff, or other advocates concerned about the impact of direct-care job vacancies and turnover on consumer care, three — the Connecticut Association of Personal Assistants (CTAPA),¹¹ the Virginia Association of Professional Nursing Assistants, and the National Association for Direct Care Workers of Color¹² — were founded by direct-care workers who recognized the need for an organization for themselves and their peers.

Several of the newest groups — including associations in Maine, Vermont, and North Carolina — were funded by Real Choice Systems Change grants from the Centers for Medicare & Medicaid Services (CMS). That accounts for much of the

recent focus on non-facility-based care, since the Real Choice grants were designed to promote the development of home- and community-based delivery systems.

The Benefits of Direct-Care Worker Professional Associations

Professional associations are a long-established tradition for most types of people who work in long-term care. The approximately 500,000 nurses in the field, for example, may choose between associations for directors of nursing, gerontological nurses, nurses who work in assisted living, nurses who fill out minimum data set charts in nursing homes, and nurses who specialize in wound, ostomy, and continence care. By contrast, only a few thousand of the approximately two million nursing assistants, home health aides, personal assistants and other direct-care workers who provide an estimated 80 to 90 percent of the hands-on care and services in long-term care belong to professional associations.

Unlike labor unions, professional associations do not represent workers to an employer as a legally recognized bargaining agent. Workers may belong to both a union local, which represents them to their employer in matters related to wages, benefits,

and working conditions, and a professional association, whose purpose is to support direct-care workers in a particular state or region.

The specific benefits offered by professional associations range from educational seminars to affordable health insurance, but the underlying principle is always the same: to provide members with opportunities for professional growth.

Networking is one of the primary attractions of a professional association, especially for home- and community-based personal assistants, since they tend to be isolated from their peers. Regional meetings, national and statewide conferences, newsletters, electronic listservs, websites, and peer mentoring programs offer association members ways of sharing ideas with and learning from other workers.

Another key benefit is the opportunity to refine professional skills or learn about new theories and practices. Many direct-care worker associations offer educational workshops, which supplement rather than replace training provided by employers or required by the state. These programs may be of particular use to home- and community-based workers, who generally receive less formal training than their facility-based counterparts.

Professional associations also help members hone a sense of pride in their work. Many direct-care workers join such groups because they are seeking respect for the work they do. In a professional association, they find like-minded people who share their belief that what they do is a calling as well as a profession, that it takes skill and compassion, and that their contribution to long-term care deserves to be recognized. "The number one

"Maine PASA has given me a chance to possibly make a difference in the effects of my work world of the elderly. I will learn some skills I never dreamed of, and having girlfriends younger than 70 is wonderful."

— *Roberta Record, PCA and Maine PASA member*

reason for CNA turnover is not the pay, it's not the short-handedness. It is the low self-esteem, the not valuing themselves," says former CNA Lori Porter, the co-founder and CEO of NAGNA. "People want to feel important, and the only way to do that is through a professional association."

In addition, professional associations provide workers with opportunities for developing their leadership abilities and strengthening their collective voice. Most professional associations for direct-care workers advocate for better wages and benefits, working conditions, and career opportunities. In a number of states, direct-care worker associations have brought workers into critical debates about the future of long-term care.

By empowering and educating workers, motivating them to stay in the field, and adding their critical perspective to discussions about job and care quality, professional associations for direct-care workers benefit other stakeholders as well. Addressing Maine's Personal Assistance Services Association (Maine PASA) in November 2003, Christine Gianopoulos, director of the Bureau of Elder and Adult Services of Maine's Department of Aging, noted that associations like Maine PASA can be a valuable conduit for "bringing workers' voices into the conversation about how to provide adequate support and assistance to elders and people with disabilities." In order to solve that pressing problem, she added, "We need everyone at the table — including workers and consumers."

Organizational Models

A look at three state groups illustrates the range of activities and organizational models that professional associations for direct-care workers are adopting.

- Manchester, Connecticut-based CTAPA, which represents personal assistants who provide consumer-directed care, created a structure that mirrors that model's emphasis on consumer involvement. Launched in 2002, the group holds monthly meetings just for workers and quarterly meetings for both workers and employers (who, within the consumer-directed model, are the consumers themselves). At the meetings for both workers and consumers, all attendees engage in a group discussion and then split into two separate groups, one for workers and one for the consumer-employers.

CTAPA offers workers several benefits that are rarely available to personal assistants who provide consumer-directed care: It gives them a chance to share information, ideas, and support with their peers, both at meetings and through a quarterly newsletter and a website, and it offers them a chance to purchase relatively low-cost health insurance. A state bill passed in fall 2003 allows any personal assistant in Connecticut who belongs to a professional association to purchase health insurance through a municipal health insurance plan. CTAPA is not referenced in the bill, but it is the only association in the state representing personal assistants. The lawmakers presumably identified the association as a trustworthy vehicle after CTAPA members helped educate them about the need for better health care benefits for personal assistants.

What Workers Want

A list in the first newsletter published by the Maine Personal Assistance Services Association summarized what workers at an inaugural meeting said they wanted their association to do for them:¹³

- Empower us to preserve human dignity.
- Help us address issues like continuity of care and short staffing.
- Give affirmation.
- Help us make changes.
- Provide comradery.
- Other people will view us as professionals.
- Other people will see us as valuable.
- Other people will see the people we serve as valuable, including older people [and] people with disabilities, both children and adults.
- Our voices could be solidified (and unified) and people would listen.

And what would the workers tell people, once they had their ear? "Pay us what we're worth," the list concludes. "Treat us better in other ways also — give us more positive feedback."

- The Winter Haven-based Florida Association of Nurse Assistants (FANA)¹⁴ began in 1995 after founder Margaret T. Carleton-Bucher held discussions with nursing assistants and home health aides in long-term care, acute care, and home health settings. After hearing consistent concerns about heavy workloads, lack of recognition, communication problems, and other roadblocks to providing high-quality care, Bucher decided to start a county-level educational support group to empower nursing assistants by enhancing their skills and professionalism.

The group, then called The Nurse Assistant Educational Support Group, formed committees to plan educational programs, develop and stage an annual convention, and develop a code of ethics for nursing assistants. Its offerings proved popular, and in 1997 it changed its name and incorporated as a statewide organization, but its primary focus has remained regional. FANA now has more than a dozen chapters throughout the state, each of which holds educational meetings covering both clinical and relational skills.

- Portland-based Maine PASA¹⁵ is just a year old as of this writing, but it has already made an impact. Funded by a CMS Real Choice Systems Change grant aimed at expanding the pool of qualified personal assistance workers to provide home- and community-based care, the group intends to foster educational and professional growth and give workers a conduit for joining the debate over government policies that affect them. Its newsletter is mailed to 350 workers and other interested parties, and its annual statewide conference has proved

successful in bringing together workers from Maine's many rural communities.

Maine PASA members are weighing in on issues concerning the workforce at the legislative level as well. Testimony by one member against a proposed bill that would have required almost all of the state's personal assistants to be certified as nursing assistants, for instance, helped convince lawmakers to table the proposal. Other members are serving on the Maine Joint Advisory Committee on Select Services for Older Adults, a committee appointed by the legislature to study care options for people with dementia. "PASA means opportunity," says member Trish Richard. "Opportunity to educate other workers, to educate the public. Opportunity to share my passion, to foster professionalism."

Getting Started: Organizing and Sustaining a Worker Association

Professional associations have enormous potential as vehicles for supporting and empowering direct-care workers, but organizing an association takes substantial effort and commitment from workers as well as those who support them. It also requires at least a minimum core of resources. NAGNA's Porter recommends that organizers line up some funding and have a plan for how to get the rest that they'll need before launching. "We probably could have been a lot

better off if we'd had money from the start," she says. Rose Marie Fagan, who founded a now-defunct caregiver association in New York state, says she would start by lining up a few key players and some funding if she were starting a direct-care worker association today. "I would want to have a core group of CNAs — either currently working or retired — that were going to stay with us come hell or high water," she says. "Next, carefully select an advisor or advisors. Then seek funding."

Most new direct-care worker professional associations will face the following issues as they begin to organize. Addressing these challenges early on can increase the likelihood of success.

Defining the Association's Vision and Mission

Before forming an organization, it is important to explore the concerns of the workers the association hopes to recruit as members. If you plan to include workers from various settings, explore whether they have differing concerns. Ask why they would join an association and what would appeal to them most. Do they want training? Avenues for improving wages and benefits? Something else? The organizers of the Professional Caregivers Association of Vermont (PCAV), for instance, conducted listening sessions before they started their organization and learned that lack of respect was the workers' main concern.

Once a core group of members has coalesced, the next step is to clarify the association's goals by writing a mission statement (see sidebar) and defining specific objectives. It's a good

idea not to try to do too much at first, concentrating instead on just one or two key objectives until the organization has gained some visibility and a measure of financial stability.

Defining the Membership

One of the most critical questions a direct-care worker association must answer early on is who its members will be. Will it include direct-care workers across all long-term care settings or only those who work in a certain type of setting? All direct-care workers confront similar obstacles on the job, but there are many differences as well. Workers employed directly by consumers, for example, tend to have a different understanding of concepts like "training" and "professionalism" than people who work under the direction of a nurse. An all-inclusive association will need to promote dialogue so that workers can understand each other's concerns.

Professional associations for direct-care workers must also decide whether consumer-employers, agency staff, or other stakeholders will be invited to be members. There are compelling reasons to include employers, starting with the fact that winning their support makes it much easier to establish an association and keep it running. Some observers believe, for instance, that a New Hampshire direct-care worker association that disbanded in 2002 dissolved in part because employers saw it as a threat. CTAPA found that very few personal assistants

were able to find time to attend its meetings until their employers were invited to join them.

Finding Members

Recruiting workers to join an association is not an easy task. Simply locating workers can be challenging, particularly if they work for individuals or small and geographically scattered organizations. Most professional

associations start with a grassroots effort, organizing meetings of workers on a local or regional level. Other avenues include running notices in local papers or in other long-term care organizations' newsletters or handing out literature at a conference for ombudsmen or other long-term care professionals to reach people whose work brings them into contact with direct-care workers.

Probably the best way to reach workers is through their employers. Employers can help distribute association brochures and meeting announcements. They can allow employees to attend meetings during work hours, making it much easier for workers to participate. What's more, workers are more likely to feel comfortable about joining a professional association that their employer endorses. To encourage employer support, many association leaders approach employers directly, talking to them about how a professional association can improve direct-care workers' skills and reduce turnover. It's also a good idea to address employers' fears — for example, letting them know that associations do not foster discontent, and in fact, workers who join associations often stay longer with their employers.

"Belonging to a professional organization is an important part of anyone's career growth and validates the worker in a unique way. Recognition is about being nice and thanking workers for their efforts. It's also about gaining visibility for their issues and about validating the workers in this system in a way they might not have otherwise."

— *Genevieve Gipson, executive director of NNCNA*

Communicating the Benefits of a Professional Association

Once you've found workers, it's usually a challenge to convince them to join an association, especially if they're being asked to attend meetings or do extracurricular work to support the group's efforts. Direct-care workers' lives tend to be crowded by competing responsibilities, making it difficult to take on a new obligation. What's more, many fail to see how the time they're being asked to invest in an organization would pay off.

To disseminate a clear, consistent message about the benefits they offer, associations like FANA, CTAPA, and North Carolina's Direct Care Worker Association have created inexpensive three-fold brochures that they use to recruit new members. CTAPA's brochure, in addition to describing the association's primary activities, identifies six reasons for direct-care workers and their employers to join their association: 1) Meet other personal assistants who understand your situation; 2) Tap into a network of people with disabilities who are looking for personal assistants to work for them; 3) Learn what is happening at the state and national levels around personal assistance services; 4) Join with other personal assistants to advocate for better pay and benefits; 5) Get your questions answered about the waiver programs in Connecticut; and 6) Make a difference for yourself and others.

In addition to brochures, some direct-care worker associations have developed websites to communicate their mission and vision and the benefits they offer their members.

Scheduling Meetings

Finding a time and place when members can meet is a significant challenge for direct-care worker associations, whose members work in a 24-hour-a-day, 7-day-a-week profession, often hold two or more jobs, and cannot always afford the cost of transportation or child care to attend meetings.

Some organizations pay workers a stipend for attending meetings, which makes it easier for cash-strapped workers to justify the time they spend there. Others meet at unconventional times. Maine PASA, for instance, has had success with Saturday morning breakfast meetings.

Scheduling annual conventions poses another set of challenges. Since travel and lodging costs can be prohibitive for low-wage workers, many associations either set aside some funds or enlist a sponsor to help cover attendance costs.

Finding Funding and Other Resources

Unlike trade associations or associations for highly paid white-collar workers, whose members can afford to pay three-figure annual fees, professional associations for direct-care workers cannot survive on dues alone. Unfortunately, other forms of funding are in short supply and do not last indefinitely. Direct-care worker association coordinators recommend lining up funding as early as possible — preferably before convening your first meeting. They also recommend looking for multiple sources of funding in order to avoid being overly dependent on any one source or bound by potentially restrictive requirements.

Mission Statements

Most direct-care worker professional associations develop a mission statement early on, to help set goals and guide activities. Here are a few examples:

The Iowa CareGivers Association

Enhancing quality of care through dedication to the direct-care worker and all caregivers.

Maine Personal Assistance Services Association

Maine PASA is organized to empower workers, build opportunities, respect human dignity, and improve the quality of our jobs.

National Association of Geriatric Nursing Assistants

To elevate the professional standing and performance of CNAs through recognition, advocacy, education and empowerment while building a stronger alliance with health care providers to maximize success and quality of patient care.

Direct Care Workers Association of North Carolina

To improve the quality of care by promoting the interests of direct-care workers through education, professional development, and public awareness.

Groups that fund efforts to develop the workforce or empower low-income women or women of color are good candidates for grants.¹⁶

The story of Fagan's organization, the New York State Certified Caregivers Association, illustrates the importance of lining up adequate funding early on. Fagan founded the association in 1998, bringing together CNAs from area homes engaged in a culture change process. With coaching from Fagan and a part-time advisor, the CNAs set their own agendas and ran their monthly meetings. The group also published a worker-written newsletter, which grew in both circulation and frequency, and hosted an annual conference for CNAs.

Fagan patched together funding to support these activities from various sources. Lifespan, her employer at the time, subsidized the time she spent running the project and coaching association members, and the New York State Health Care Association sponsored some of the group's activities. Two small grants from groups that support initiatives aimed at empowering women helped pay for a part-time advisor and a part-time assistant. But just when the group was about to solicit newsletter ads to help cover the cost of production and capacity-building grants to allow the caregiver association to grow and to become self-sustaining, the attacks of September 11, 2001, took place, and the flow of nonprofit funding slowed to a trickle in New York. With its existing funds dried up and nothing emerging to take their place, the group disbanded in 2001.

The experience of the New York Certified Caregiver's Association also illustrates the importance of collaborating with

a community organization that can provide the office space and equipment that direct-care workers rarely have access to — and perhaps even more importantly, the help of a part-time or volunteer staff person with experience in running similar projects. Maine PASA Project Coordinator Elise Scala, who is on the staff of the University of Southern Maine's Edmund S. Muskie School of Public Service, uses university resources (facilities for business meetings, technical support, and graduate assistants) as well as her own time and expertise to coordinate Maine PASA's activities.

Scala has also convened a group of people involved with other professional associations for direct-care workers to identify “common experiences and challenges involved with developing the associations and coordinating direct-care and support workers” in monthly conference calls and ad hoc conversations and e-mails. The information she has picked up in these exchanges, she says, has convinced her that all direct-care worker professional associations would benefit greatly from maintaining contact with people who are engaged in the same kind of work in other regions.¹⁷

In addition to educational institutions, possible partners include local and state long-term care ombudsman programs, state Medicaid agencies, and agencies serving the elderly or people with disabilities. Some national organizations, such as the National Alliance for Direct Support Professionals,¹⁸ a coalition of individuals and groups from fields including mental health, developmental disabilities, child welfare and education, and the Direct Care Alliance,¹⁹ a multistakeholder coalition supporting quality jobs for direct-care workers, also provide non-financial support to state and local caregiver associations. Collaborating with such organizations connects direct-care worker associations with a network that makes it easier to learn about and participate in statewide and national activities affecting their members.

Maintaining Worker Control

If a professional association is to be an effective vehicle for growth and empowerment, it must do more than just advocate for direct-care workers or provide them with educational programs or other benefits. Workers must play a central role in defining its objectives and activities, and that means the association must find ways to develop workers' leadership skills. “There's a lot of groundwork that has to be done, and a lot of skill-building, so they're able to be autonomous,” says Fagan. “Too many people want to do for them. You want to lead from behind and build their capacity.”

Having direct-care workers control the majority of seats on the professional association's board of directors or steering committee is essential, but it is only a start. Some direct-care workers may not have experience shaping agendas or doing the

other organizing tasks needed to maintain a professional association. What's more, most are unaccustomed to having their opinions solicited in matters concerning their work and have not had training in team building or leadership. If other stakeholders involved in an association have experience in these areas, they may be tempted to take and run things “for” the workers — but giving to that impulse means sacrificing long-term efficacy for the sake of short-term efficiency.

Direct-care worker associations that encourage employers or other stakeholders to join must be particularly careful to ensure that control of the association remains with the workers. Vermont's PCAV, for instance, decided that its steering committee should consist only of people who are currently employed as direct caregivers, and one of its first activities was a facilitated retreat for new members at which the focus was on helping

workers take charge of the association. Another solution is to make other stakeholders eligible for a category of membership that does not include voting rights, as North Carolina's DCWA does.

Many organizers of professional associations for direct-care workers report that developing individual workers' skills in areas like public

speaking, running meetings, and designing an organizational strategy is one of their main goals, since workers rarely have a chance to develop those crucial skills elsewhere. Leadership training, coaching, and appointing a skilled facilitator to run meetings can all help. Maine PASA, for example, has focused much of its early efforts on developing the self-esteem and leadership capabilities of its core members. Convinced that being truly worker-run is critical to success, Scala has made sure that the workers have the support they need, through coaching and skill development, to plan and write their organization's newsletter, organize an annual conference, and speak at a variety of public forums.

An organization's day-to-day culture must also be structured around its members' needs. Planning meetings around workers' schedules and making sure they have resources to attend sends the message that the professional association belongs to them, as does ensuring that caregivers' views are always given priority. If workers are encouraged from the start to take ownership, planning and leading initiatives and setting the association's long-term agenda, the association has a much greater chance of serving workers' needs, attracting a broad membership, and becoming a strong advocacy voice for quality jobs and quality long-term care.

Conclusion

Professional associations for direct-care workers represent a fairly recent and innovative response to the challenge of building a more stable direct-care workforce. By providing workers with needed supports, freeing them from professional isolation,

“NAGNA is all about empowering the CNA with knowledge that their voice means something, that they have something to say and they deserve to be recognized for all that they do. The more empowered we are, the better we will be heard by those [who] are making the decisions for our elderly and those that care for them.”

— Lori Drummond, CNA and NAGNA member

and providing a channel by which they can both advance their own careers and improve the quality of the job as a whole, professional associations give dedicated workers more incentive to remain in the field. “It’s immensely helpful to have a voice when it comes to legislative action, and to have a voice for the worker,” says Maine PASA member Trish Richard, who has provided services to people with disabilities for 20 years. “If I hadn’t had the backup support finally, after 20 years, that the association can offer, I would have left — and I love my job.”²⁰

Endnotes

1. U.S. Bureau of Labor Statistics, Economic and Employment Projections, Table 3b: *Fastest growing occupations*, 2000-10. Found online at www.bls.gov/news.release/ecopro.t06.htm November 25, 2003
2. Robyn I. Stone and Joshua M. Weiner, *Who will care for us? Addressing the long-term care workforce crisis* (The Urban Institute and the American Association of Homes and Services for the Aging, October 2001).
3. For more information, see *State Wage Pass-Through Legislation: An analysis*, found online at <http://www.directcareclearinghouse.org/download/WorkforceStrategies1.pdf>
4. For an overview of career ladder initiatives, go to www.directcareclearinghouse.org/r_cat_det.jsp?cat_id=4110
5. Throughout this brief, the terms “professional association” and “direct-care worker association” are used interchangeably to refer to professional associations for direct-care workers.
6. www.cna-network.org
7. www.iowacaregivers.org
8. www.nagna.org
9. BJBC (www.bjbc.org) is a four-year research and demonstration project aimed at reducing high vacancy and turnover rates among direct-care staff across the spectrum of long-term care settings and contributing to improved workforce quality.
10. Contact information for all current worker associations, as well as links to more information about many, can be found on the National Clearinghouse for the Direct Care Workforce website at www.directcareclearinghouse.org/worker_assoc.jsp and at www.hcbs.org. Longer descriptions of selected groups may be found in *Direct Care Worker Associations and Public Authorities*, a report by Jennifer Gillespie of the National Academy for State Health Policy, found online at www.nashp.org/Files/Direct_Care_Worker_Issue_Brief_FINAL.pdf
11. www.ctapa.org
12. www.directcareworkersofcolor.org
13. *Maine Personal Assistance Services Association News* (November 2002). Found online at <http://qualitychoices.muskie.usm.maine.edu/Access/pasa/Nov02.pdf>
14. <http://hcassidy.tripod.com/FANA/FANA.html>
15. www.maine-pasa.org
16. Rose Marie Fagan recommends contacting the local branch of the American Association of University Women (www.aauw.org), which provides not only funding but also training to help women develop new skill sets.
17. Personal communications with Elise Scala, September and November 2003.
18. www.nadsp.org
19. www.directcarealliance.org
20. Personal communication, October 8, 2003

Resources

Setting up regional chapters

FANA director Terry Bucher has created a three-page guide to setting up a regional chapter. All new chapter officers receive a copy of the guide, which outlines how to convene a planning meeting and set an agenda and lays out the responsibilities of the facilitator, assistant facilitator, host site, and state association office. They also get a sample copy of an agenda, rules for conducting a meeting, and forms for writing minutes, meeting summary sheets, finance reports, and public releases. For a copy of the chapter guidelines, contact Bucher through <http://hcassidy.tripod.com/FANA/FANA.html>

Establishing nonprofit status and related questions

Links to information on how to form a nonprofit, including sample bylaws and a step-by-step guide, can be found at www.uwex.edu/li/learner/sites_start.htm

Information on how to obtain nonprofit status, materials on lobbying, and other resources for nonprofits are available from the Alliance for Justice at www.allianceforjustice.org/nonprofit

In *A Voice for Nonprofits*, authors Jeffrey M. Berry and David F. Arons analyze the effect of government restrictions on the participation of nonprofits in the policymaking process and suggest ways to address the problem. To order a copy, go to www.brook.edu/press/books/voicefornonprofits.htm

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The nonprofit Paraprofessional Healthcare Institute (PHI) focuses on strengthening the direct-care workforce within our nation's long-term care system through developing innovative approaches to recruitment, training and supervision; client-centered caregiving practices; and effective public policy. To learn more about PHI or the CMS-funded project *Research on the Availability of Personal Assistants*, go to www.paraprofessional.org or call 718-402-7766.